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Children and HIV in Scotland

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Background

- A cross-sector needs assessment
- Aim to provide up-to-date information about infected and affected children
- To inform policy and practice
- Initiated and funded by the Elton John AIDS Foundation
- Supported by a Steering Group of local HIV agencies



The study

- 3 parts:
 - Scoping study
 - Epidemiological surveys of infected and affected children
 - Interviews with practitioners, parents and carers, children and young people
- Terminology: infected and affected
- Timescale: February to July 2009



Epidemiological survey 1

- Children infected with HIV – data from:
 - Health Protection Scotland
 - Institute of Child Health (London)
 - Paediatric clinics
- Numbers: 35, 43 or 47 infected children



Age and ethnicity

- No children born in Scotland with HIV since 2001
- 2 distinct groups of infected children and young people:
 - Younger children, born outside Scotland (mainly black African)
 - Older young people, born in Scotland



Epidemiological survey 2

- Children affected with HIV – data from:
- Questionnaire survey of HIV service providers in Scotland
- Following up and extending 1996 survey on affected children
- Estimates around 833 affected children



Age, ethnicity & region

- Overall decrease since 1996 survey
- Large increase however in Greater Glasgow and Clyde Health Board
- Rise in under 5s in Greater Glasgow and Clyde and Lothian, and these are largely black African children
- Decrease in Tayside
- Small pockets throughout Scotland
- Note for future – there has been a significant rise in adults receiving treatment for HIV – hence a rise of affected numbers is predicted



Qualitative study: interviews

- 20 practitioners
- 16 parents and carers
- 5 children and young people infected with HIV
- 7 children and young people affected by HIV



Findings 1: Practitioners

- There are very few services (except for health services) that focus directly on children who are infected or affected
- There is a lot of inter-agency work but collaboration can be difficult
- Children want same things as other children
- Need for transitional services for teens
- Children need to be able to access safe, non-stigmatising services
- More public awareness is needed



Findings 2: Parents and carers

- 'HIV is an illness of uncertainty and hardship and that's bound to affect our children in every which way.'
- There is a lack of services in the West of Scotland: 'We don't want anything for ourselves; we just want something for our children.'
- Stigma remains: 'It's still very much there, you have to keep it secret, it's a constant, it's as strong as it ever was.'
- Parents and carers want time for children to have fun AND to get support around HIV



Findings 3: Infected children

- 'I want to be like the others in my class, same well like them, same well like other childrens.'
- 'People just try to make the world so complicated, but everything is normal if you want it to be. [...] HIV is just normal, you don't have to make a fuss about it - like on TV when they talk about HIV, they just try to make out as if it's the end of the world, but it isn't.'
- But... medication Also stigma & secrecy



Findings 4: Affected children

- '[My life] was quite different to other children. I mean, everybody's got their problems. I just feel that because mine was such a big secret, I couldn't tell anyone about it.'
- 'It's weird talking to someone, because I've never really talked to anyone about my mum's HIV, or my feelings about it. It's like if you've never driven a bike and someone suddenly gives you a bike to ride. It's a bit weird.'



Moving forward

- Children are invisible in HIV and children's services
- They have specific needs in relation to age and ethnicity and those with HIV have clinical needs
- There are regional differences across Scotland
- Parents and children need support for disclosure & there needs to be a public education campaign to challenge stigma
- Need for more consistent data collection
- Need for continuing coordination across different sectors



Thanks

- Thank you to all the practitioners, parents and carers, children and young people who took part in the study
- Also to our funders (EJAF) and to the University of Edinburgh for supporting the study
- Thank you all for your attention – we look forward to discussing further the issues with you in the next part of the seminar